



Queensland University of Technology
Brisbane Australia

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Wilson, Jill, Tilse, Cheryl, [Purser, Kelly](#), & Yellowlees, Josephine (2014)

Journeying into the future: Parents' succession planning for their adult children with cognitive impairment.

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<http://www.communityliving.org.au/wp-content/uploads/2014/10/Journey-into-the-future.pdf>

**Journeying into the future:
PARENTS' SUCCESSION PLANNING
FOR THEIR ADULT CHILDREN
WITH COGNITIVE IMPAIRMENT**



**A joint project of The School of Social Work and Human Services,
The University of Queensland and the Australian Centre for Health
Law Research, Queensland University of Technology**

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July 2014**

Cover page artwork

‘Story Bridge’

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Glossary

Discretionary trust: ‘A trust in which the trustee has a discretion as to: when any payment from the trust fund will be made; who, in a definite class of beneficiaries, will receive it; and the amount of such payment’.

Special disability trust: <http://www.humanservices.gov.au/customer/services/centrelink/special-disability-trusts>

A Special Disability Trust must:

- have only one principal beneficiary (the person for whom the trust is established), who must meet the eligibility criteria
- provide for the accommodation and care needs of the principal beneficiary
- have a trust deed that contains the clauses as set out in the model trust deed
- have an independent trustee, or alternatively have more than one trustee
- comply with the investment restrictions
- provide annual financial statements and
- conduct independent audits when required’
-

Testamentary trust: ‘A trust created by a will or codicil.’

Short Report: Parents' Succession Planning for their Adult Children with Cognitive Impairment

This report documents the findings from a cross disciplinary project, titled '*Parents' succession planning for adult children with a cognitive impairment*'. The project, conducted between October 2013 and May 2014, was a joint collaboration between The School of Social Work and Human Services, The University of Queensland and the Australian Centre for Health Law Research, Queensland University of Technology. The focus of the research was to investigate the legal and social issues facing ageing carers in planning for the future care of people with a cognitive impairment when they are unable to continue to provide care themselves. An issue of increasing interest to government, the aim of this research is to provide key messages and recommendations for policy and practice. The research team comprised Professor Jill Wilson and Associate Professor Cheryl Tilse and Dr Josephine Yellowlees, School of Social Work and Human Services, The University of Queensland and Dr Kelly Purser, the Australian Centre for Health Law Research, Queensland University of Technology.

Introduction

The need for future planning and the issues facing ageing parents of people with a disability are increasingly recognized in policy and practice. The Senate Community Affairs Reference Committee recommended facilitating future planning in their 2011 report. The government, in their 2012 response, agreed to further consider this, noting that developing innovative approaches to future planning is a priority area for State, Territory and Commonwealth governments. How this will work with the policy changes relating to the National Disability Insurance Scheme and current systems of administration and guardianship requires greater understanding. The perspectives and experiences of parents and service providers also need to be taken into account in developing a succession planning framework that is appropriate and accessible. The study aims to provide a basis for such framework by clarifying, and assessing the legal options available; and determining peoples' current experiences and expectations. Parent interviews explored their experiences in accessing advice, their understanding of planning options available to them such as provision through wills and trusts, and their evaluation of the quality of their experiences. Similarly although not reported here, staff interviews explored their understanding of these issues for parents in planning and decision making. Findings indicate that for parents the pursuit of a quality life for their child with cognitive impairment is of paramount concern in their future planning. As such, quality of life emerged as the primary theme informing parents' decision making and planning. However findings also evidenced areas of unmet needs regarding access to professional information and advice that is timely, appropriate and consistent, impacting parents' capacity to plan effectively.

The Key Themes

The following key themes emerged from the research interviews with parents.

1. Quality of Life: Values and Ideals Informing Parents Decision Making

Primarily, for interviewed parents, decision making in planning for their child's future was premised upon ideal outcomes based on their values and the perceived quality of life they envisaged for their

child. For parents the following criteria were important in achieving their ideal outcomes: **respect, dignity, independence, social inclusion, key associations, choice in decision making and place to call home - 'a place of their own', 'a place to go to'**. Parents spoke of their hopes for their sons and daughters to enjoy, comfort, safety, meaningful relationships and financial security. These values and ideals underpinned parents' decision making in establishing and optimising their child's future life. For some families this meant attending to the future lives of several children with disability. The essence of parents' pursuit in seeking a quality life for their child is captured by this couple's comment:

If we can't live like that, if we don't want to live like that, why should they? That was basically our thing. Parents 4&4ap37

While most parents voiced awareness of the imperative for planning and implementing arrangements to safeguard their child's future, moving forward with decision making and planning was an overwhelming and daunting task as the following parent's comment indicates.

The future- it's this really dark place that we haven't actually addressed yet because we're still fighting against the current right now to move onto that next step. Parent 2ap25

2. Planning Decisions and Arrangements: Influences

In this second theme concerned with decision making and planning arrangements, parents were predominantly influenced by their **family values, commitment and life experiences** in seeking a quality life for their child.

We - we're family, we manage fine. But it's what you do. Parent 8p15

We worked hard as a family to get him his independence. Parent 11p10

Families like ourselves are people who've never asked for help. We've always done it ourselves and that's why you - you do as much as you can in a normal situation; Parent 5ap25

They're [family] right behind me with the philosophy. They're very supportive. They've never shown any sign of resentment Parent 12p21

Due to various and sometimes complex family arrangements and experiences in terms of support these ideals panned out in different ways. Some parents had access to family members who participate in supporting the person's life, while others did not.

Anything that we do, we try and involve [sibling] as well so she knows where we're at and she's at the same - she's on the same page. [She's] very much part of it. Parent4&4ap22, 23

We've moved away from extended family. He's very happy here and he doesn't want to move from here, [but] in the event of something happening to [us], he's here alone....which we didn't think about 25 years ago. Parent 11p11

Other parents not wishing to impinge on the lives of their family members were reticent in overly involve them in future planning.

As a family, we have some expectations, but we don't have the expectation that they have to be heavily involved when they've got their own families. Parent 13p8

Life experiences, generally concerned with family relationships, obligations, conflict and financial arrangements acted to either drive or hamper parents' actions in future planning as the following parents' comments indicate.

They're [paternal family] inheritance is just a mess from start to finish, which has really influenced ...how we've come to our decisions. Parent 6p2

Being in the accountancy field, [we've] seen some amazing things that happen within families. You might think you've got the best kids in the world, but when it comes down to financial issues, every story can look very different. So we thought that (assisting son to source accommodation) was a way of protect[ing] [him]...financially... Parent 14p6

[Partner and intergenerational responsibilities] I feel very much the meat in the sandwich and everybody's putting demands on me...everything I thought [concerned with planning] was on me to do and to organise - and then my [partner] would be resentful of the time... Parent 15p24

Furthermore, parents' often **long term engagement with the disability sector** influenced their motivation, capacity and effectiveness in planning and decision making. Where adult children received well established agency support, parents were less likely to consider the need for future planning. While some parents reported positive supportive experiences with their service providers in future planning, other parents commented on adverse experiences impacting their capacity to progress, or at least progress effectively, with future planning. For example parents commonly reported that information provided by the disability sector was limited, lacking quality, consistency and timeliness.

You get told things along the way but sometimes they're right, sometimes they contain various levels of truth. It'd be nice, be real nice, that - if you actually got told something, that you had a fairly good assurance that it was correct. Parent2p26

Yes. It's just an ongoing battle ...with conflicting messages, which leads to being unable to have a firm plan...the information should be out there and it should be clear. Parent6p15-16

2a. Key factors informing parent decision and planning arrangements.

Four primary areas emerged as priorities for parents in their decision making and planning arrangements around seeking a quality future life for their child; **accommodation, independence and social connectedness underpinned by financial security and support.**

a) Accommodation was the foremost priority for parents. Common aims centred on quality and appropriate accommodation providing stable, safe and secure tenancy. Ease of access to transport, services, family and community were important considerations. Parents often engaged in challenging, complicated, time consuming and resource intensive processes to source suitable private or publicly available housing for their adult children.

However, regardless of the form of sourced accommodation, further concerns emerged with respect to adequate resourcing and tenure. For example concerning private ownership, issues arose for property administration and maintenance, and the potential for tension and conflict among family members as beneficiaries. Those with access to social/ public housing, including agency supported accommodation, expressed vulnerability to government and policy changes impacting stability in tenure.

My plan is that [daughter] will continue to live in the house. I've left that to her as a life interest and I've left what money I have to her, to help her maintain the house. Parent 1p6
This is the Housing Commission house ...he has it for 10 years ... we're not sure what's going to happen....but we're hoping he'll stay here. Parent 12p10

b) Independence emerged as a further primary concern for parents. Securing appropriate accommodation was a significant step for parents in promoting their child's independence. Parents valued and promoted opportunities for their child to have a voice and choice in decisions about their own lives, although among the study's parent cohort, differences existed in their expectations for independence.

So, our vision is for [him] ... to be as independent as possible. Parent 5ap5

What we want for her is dignity and independence. My ideal for her is to be able to be confident to live independently...and to feel like she's actually making decisions in her life.

Parent 7&7app8,9

Education and life skill development were ongoing projects for many parents in preparing their child for independent living. General skills include shopping and cooking, access to transport, and management of their home, finances and health. In some instances parents engaged in creative opportunities to encourage their child's social and financial independence and to achieve an 'age appropriate life'. Examples include: a business development initiative based on the person's artistic skills and the employment of a project worker to assess appropriate and feasible opportunities to enhance the person's lifestyle.

c) Social Connectedness was a third key priority for parents. Social networks, community visibility and safe, sustainable, meaningful relationships were vital to parents concerned for social interaction, advocacy, problem solving, safety, loneliness, and achieving their child's wants and needs. Variety in social inclusion measures on a range of levels was important to parents; for example, sibling and family relationships, personal friendships and relationships, committed mentors and support carers and broader community social engagement through special interest groups. Social connectedness was a constant, consistent anxiety among all parents and they worked hard with sustained effort to create, develop and maintain their child's social networks.

Social connectedness and independence, are really the key goals Parent 9p23

We've built is quite a network of support around [son]. Parent 12p10

d) Financial Security emerged not as a priority for parents but rather a concern underpinning their children's quality of life - linked to appropriate and stable accommodation, fostering independence and social connectedness. Financial support for ongoing property administration and maintenance was worrying for parents who made private housing arrangements. For parents whose children reside in social housing, the uncertainty of longer term tenancy raises anxieties for potential future financial resources. Parents valued continued access to the Disability Support Pension (DSP) and funding support. Although it was understood to provide minimal income, parents considered the Disability Support Pension a safety net and formal link to government and government services. For these reasons, even where a substantial inheritance was due to the person with the disability, parents were keen to retain access to the DSP. Access to Funding packages for use in carer support and social engagement was of interest to parents seeking quality of life. Financial security appeared less concerning for parents of adult children who receive substantial support from their disability support agency.

One of my fears is that he lose the pension which provides a support network for him. Parent 2ap14

We thought...to have his own home/unit...was a way of protection for [son] financially, Parent 14p6

2b. Professional Advice: Lawyers, Medical Practitioners, Accountants and Financial Planners

In achieving their goals and ideals for their children, parents were asked about what, if any, professional advice was sought from medical, legal and financial professionals (accountants and financial planners). In particular parents were asked about any legal or financial mechanisms they might have employed to assist them in their decision making and planning processes.

Overall, few interviewed parents reported engaging with these professions to inform their decision making and future planning. Reasons voiced were a general lack of trust in these professions and in particular a perceived deficit of professional knowledge of the disability sector.

No, we haven't spoken to anyone [professionals] mainly because we can't identify anyone with enough knowledge, that's got an understanding of the whole picture, because we don't.
Parent 2ap20

Of the professions asked about, legal practitioners were most likely sought by parents typically concerned with will making advice. Some parents sought legal advice through The Public Trustee and one family accessed an earlier legal/disability planning pilot project supported by a private legal firm. Overall medical practitioners and specialists were not involved in future planning discussions. Rather their expertise was only sought regarding general health matters and ongoing management of chronic medical and mental health conditions which are commonly experienced among this group of people. Financial planners, rather than accountants, were accessed on occasions for financial advice, although usually regarding parents' own financial arrangements, particularly at retirement. Some parents reported accessing advice from family and friends with professional expertise. The cost of professional services was often cited as a prohibitive factor in access to professional advice.

2c. Legal and Financial Planning Mechanisms: Wills, Testamentary and Special Disability Trusts.

Parents engaged with a limited range of legal and financial mechanisms in planning for their child's future. Mostly parents focussed on will making and to a lesser extent on trust mechanisms. While many parents voiced interest in investigating and establishing trusts, to date only one Testamentary Trust and no Special Disability Trusts are in place.

a) Wills. The majority of parents reported having at least made a will during their lifetime.

However for many parents these wills were now outdated and did not reflect their current situation. Where parents possessed wills and that related to future planning, most prioritised their disabled child [ren]'s interests in proportioning their estate. Some parents firmly valued equal distribution of their estate amongst siblings with no special provision for their adult child. That said, these adult children were likely to be well established recipients of disability support and services and /or through planning initiatives have already received family support.

What we've done in our wills is that most of my funds go to [child with disability] Parent 10p12

It's always been as equal, and I don't consider that that would ever change. Parent 13p8

- **Family provisions applications.** Across the parent group there appeared limited awareness of family provision applications and the potential for will challenges. For example the following beliefs were held about estate planning;

- an estate divided equally and fairly among siblings gave no cause for challenge

- family values of commitment and respect for parents decisions limited potential for legal challenges

b) Testamentary/ Discretionary Trust. The more complex legal and financial trust arrangements were not a planning mechanism generally considered by parents. One interviewed couple had established a Discretionary Trust and another parent reported progressing arrangements for a trust. In both instances, these parents had additional access to legal advice.

c) Special Disability Trust: There were no established Special Disability Trusts among the interviewed parents although this form of planning mechanism was of interest to some. Two families reported approval to establish a SDT but had not progressed with the applications. Several parents considered the complexity and financial resources required to initiate this trust as prohibitive while others were keen to source further information.

d) Other: One interviewed parent reluctant to engage with traditional disability services is proactively engaged in researching the possibility for establishing an independent company managed by a micro-board. It is envisaged the board in managing her child's future care and support would comprise family members and external persons with specialist expertise.

3. Parent's Planning Experiences.

3a) Demands and Challenges to Effective Planning

For some parents, in the longer term, planning outcomes have brought satisfaction and pleasure to themselves, their adult child and their families. Predominantly however, *planning experiences were described as demanding, physically and emotionally exhausting, time consuming, resource intensive and challenging for personal and family relationships*. Additional demands and challenges to effective planning often being *unpredictable and unforeseen*. Reported examples included, family health crisis particularly concerning the adult child or their parent and more broadly, the implications of government policy change and global economic crises impacting employment opportunities and financial arrangements.

Child centred challenges to effective planning

Characteristics of impairment and other health conditions: It is essential to recognise the implications the child's form of cognitive impairment has for parents in their decision making planning processes, and moreover, the impact of frequently coexisting physical and mental health conditions. Parents of children with clearly observable disability and/or associated extreme behaviours were more confident about their child's continued access to government support than those parents whose children's impairment is discernable. One parent referring to her son's disability as 'invisible' spoke of the difficulties this raised not only in access to funding support but also social and employment expectations. The following comments evidence this difference.

[Her] issues are so noticeable, so profound and so well documented, that she will not have difficulty in getting support. Parent 7ap18

He doesn't fit into any of the boxes, so when the government puts out funding...he doesn't always meet the criteria. Parent 11p14

I just think that it is more complicated for someone such as [my son] who is partly competent to run his own affairs... It's an 'invisible disability'... it's not easy to put your finger on the complexity of it. Parent 15p11p37

The fluctuating and unpredictable nature of some children's health status is further challenging for these parents. Responding to health and mental health crises including violence and suicidal

behaviours, sometimes involving the criminal justice system, become urgent priorities for parents delaying and altering, future care planning, as these comments highlight.

[We] have big trauma before there's a [mental health] crisis, then there's a crisis and there's big recovery. We started the planning process about a year ago. We just started and then this blew up. Parent 7p11

I had [the bank] ringing me while I'm standing in intensive care ...these people were hammering me that, 'You're six weeks late with the mortgage payment.'...the investment for their future was subsequently sold off at less than market value. Parent 9p40

A lot of it depends on [son's] mental health and his mental state. That determines a lot of how he copes with things. Parent 8p28

Vulnerability was a significant concern for these parents where their children have limited capacity to discern undesired influences and are reliant on others for care and support. Parents raised questions about safeguarding their children and cited real and perceived situations of vulnerability including: the influence of friends/family/others, financial management, employment opportunities and conditions, disputes with other government departments for example, criminal justice and changes in government policy.

He would be extremely vulnerable for financial stuff and within the community –vulnerable more than unsafe. Parent 13p8, p15

They're all more vulnerable to any changes of policy, government. We need advocates, don't we? Parent5a p21

Parent centred challenges to effective planning

The demands of caring, requiring substantial and sustained long term effort, significantly impacts parents own resources in terms of their physical and emotional health and wellbeing including financial resources.

Physical and Emotional Wellbeing: Maintaining good health and wellbeing was important for interviewed parents in managing the current demands of caring and progressing future planning for their children. However some parents reported experiencing their own physical and emotional health crisis as a consequence of these demands and responsibilities, as described in the following comments.

I ended up with my own health crisis ... I then started having panic attacks, because I thought, if I die, what will happen to [son]? So that made my heart condition like a hundred times worse. I learned a very valuable lesson there, that you really do have to look after yourself...so I gave up work. Parent 12p24

Earlier this year I went away for three weeks - for the first time in my life I found out what it was like to worry about just me. It was like being let out of somewhere - the pain from your head that went away. I couldn't believe how different I felt as a human being. Parent 11p20

Intergenerational obligations: In addition to caring for their adult children, some parents also reported significant other caring responsibilities and obligations as their own parents and siblings age.

I just find juggling on my own. I've had my mother ill and die and before that, my sister died, my father died. It's just been oodles of things and I don't have any brothers or sisters handy that I can - put [things] onto. Parent 15p18

Financial Resources: Parents commented on the demands and challenges in managing the not in significant financial resources required in a life time of caring and in securing a financially sustainable future for their children. Parents often made critical choices regarding their own career and employment options with consequences as they age for planning their own and their child's future care. These comments reveal the critical financial issues for parents in managing the demands and challenges of longer term and future care.

I'll have to work for another 10 to 12 years in order to keep supporting [daughter], so I will have to be engaged in part-time but consistent employment. Parent 7ap5
Our position is so precarious, everything that we've got will be going into [supporting the children]. There's going to be no other way. Parent 9p45
We'd built a granny flat for [him] – [but due changes in child's health] we spent \$90,000 on something that we didn't need to spend it on. Parent 12p25.
It can be hard work, let me tell you... and it's a financial cost to us as well, and we're both retired. Parent 14p6

Practical Aspects of Planning: Commonly parents stated they did not know what was required in future planning for their child[ren] Many reported feeling overwhelmed and daunted by the perceived complexity of the issues involved. A number of parents commented that despite attending planning workshops and seminars they were still unable to identify goals and progress with a plan.

No. I really don't know what to do. [Although] we've been to various [planning] meetings from the organisations that exist. Parent 8p6
Look, yes, we know that we need to be thinking about this but at the moment, we just don't know what the future holds. Parent 9p36
It's a dilemma, dilemma... I'm feeling a bit overwhelmed. If you actually sit down and start laying down all the different aspects and thinking that I have to deal with all this...So you think, "It's all too complicated. There's too much responsibility on me." Parent 15p42

Even those parents who deliberately planned their children's lives, developed a plan and reached their goals, voiced concerns about the precariousness of their child's future when they are no longer able to advocate for them.

We deliberately planned their life and... we more or less have achieved all our goals. Now the only thing we will need to somehow ensure is when we're no longer here and that is the most difficult part.... Parent 4,4ap8

Time: 'Time' emerged as a notable and perhaps less well appreciated concept for parents in the process of planning. Parents well engaged in developing their own plans including those with expertise assisting others with life planning, viewed the process as continually evolving requiring time and commitment in achieving goals.

It was a very, very difficult journey. It took a long time to get to the point where we were doing what I wanted. Parent6p11
Sometimes that [planning] might take two years for some people. It might take 10 years for other people. Parent 13 [employed in planning facilitator role] p15

Professional (Legal and Financial) Services: Generally parents did not access professional services in their planning. However legal advice, often via family and friends with this expertise, was more likely to be sought than financial advice. Perceptions of professionals as untrustworthy, lacking

knowledge of the disability sector and costly, in terms of fees for service, acted as barriers to parents in accessing these services.

No, we haven't spoken to any [professionals] mainly because we can't identify anyone with enough knowledge, that's got an understanding of the whole picture, because we don't.

Parent 2ap20

We've rang up about three or four solicitors and we don't know how to explain to them what we're talking about. Parent 4ap44

Parents who had attempted to seek legal services often reported them as **unavailable and unresponsive**

We've tried to access them but they haven't responded. No response, or little response. ... Or their website doesn't work or something; as simple as that. Parent 5ap18

Disability Sector: Communication, knowledge and access to timely, appropriate and useful information from the disability sector were **major challenges** for interviewed parents. Parents commonly spoke of receiving confusing and inconsistent messages impacting their capacity for coherent decision making and use of already limited resources.

I think that is an area where DSQ do it appallingly...more often than not, [information's] just not relevant or appropriate. It's particularly poor. Parent 9p46

I've approached MPs, I've approached DSQ, I've approached [agencies] and Centrelink. I've had a lot of fights ... and I've won most of them. ...but I feel like I shouldn't need to because the information should be out there and it should be clear. Parent 6p16

Government: Most parents reported significant and long term engagement with government departments and officials in attempting to seek access to appropriate and ongoing services for their children. Similar to their experiences with the disability sector, parents were particularly challenged by the **lack of clear, consistent and reliable information from government at both State and Federal levels**. Especially concerning to many parents is the introduction of the Federal Government's **National Disability Scheme and what this means for them in their future planning**.

The sheer uncertainty around the NDIS and DSQ funding is quite frightening. Parent 6p14

With NDIS, you talk to people and the people who are supposed to know something about it, [but] they don't know. They can't answer your questions - that's the difficult part because you're trying to make decisions on future events ...You can't make any decisions because you don't know what they're doing. Parent 4&4ap48

Parent's planning is challenged by **changes in government policy**. For example, increases in workers penalty rates without an associated rise in funding packages impacts parents' capacity to employ care workers. Parents have little option but to take up these care hours themselves adding to rather than reducing demands as they age.

The Government refuses to increase the funding. The funding doesn't keep up with [increases in penalty rates], so we have to look at how best to manage...- well, we can't keep all the support workers for a start. We have to do more. We can't pay them. Every year gets less and less. That's something young families should be aware of. It just seemed wonderful at the time but you don't think about it. Parent 4&4ap50,51

Further, concerns were raised for the **shift of support services from government organisations to non-government agencies**. Rising administrative costs, potentially resulting in the reduction of

support and quality care and challenging parents' capacity to develop sustainable care plans were concerning as highlighted by this parent, a long time disability worker and service manager.

A major issue is that the government is farming out - their responsibilities, as I see it, so they're privatising it. So an agency becomes a support agency...So the emphasis changed from support into profitmaking. The only way they can make a profit is to reduce support.
Parent 11p28

3b) Promoting Effective Planning

Vision and goals: Having a **clear but flexible vision** of how their child's future is to look combined with an **ability to articulate needs and goals** to other involved persons and organisations, was valuable for parents as a foundation on which to build appropriate and sustainable future planning. The following comments provide parents' views on the importance of a **clear vision, identifying goals, regular plan review and mechanisms to assist in accessing resources**.

We don't know what's in front of us so we have to try and plan for what might eventuate, but it might not eventuate. But - you've still got to look at it. Parent 4&4p32

I think we've got to have a number of conceptual goals. Those goals have to be reviewed at regular intervals and then the mechanisms by which you get to those points, you don't have to understand it or know it but provided you can tap the resources that can help you align those resources. Parent 9p47

That's all part of my succession plan. I've written a document...He has a plan - he has a vision. I usually do it every two years. Parent 12p19

Health and Wellbeing: Parents own physical and emotional health and wellbeing are significant factors for them in maintaining the effort and demands required to knowledgeably and skilfully develop and implement appropriate future planning. Parents acknowledged the potential for health concerns as they age. Yet in pursuing their planning goals, several parents identified **energy, motivation and initiative** as necessary attributes which are not always compatible with ageing.

[We] are quite elderly now so it's quite difficult for us - but we have to. We know that change is part of life. Parent 4p32

It's about the momentum, keeping the momentum. That's the problem. ...if things are going well, I don't rest, I just keep going to make sure they get better. That's my big fear that the momentum won't be there [when I'm not]. Parent 12p35

Social Connectedness and Inclusive Processes: While all parents valued social connectedness for their sons and daughters, those parents who were advanced in their planning, had **embedded inclusive and social processes and practices in their planning**. Many parents taking this approach were of the view that it was commitment rather than paid work that was important in supporting their children, as this parent states.

What having a disability affected [child] has taught us is that you can't do it by paying people; you've got to find people who do more than what they're paid for. Parent 7p18

Examples described by parents included:

- investing in variations of Circles of Support comprising a range of involved people from among family, friends, current and former care workers;

- regular newsletters updating news and events in the person's life and sent out to involved and interested persons
- social activities such as as coffee at a local café, church attendance or gym membership to ensure the child is acknowledged as a member of the local community
- small businesses based on creative skills: artworks and a writing and publishing group.

Resources: Interviewed parents reported spending significant time and effort in attempt to identify and acquire appropriate resources, particularly government funding to assist in their planning. As the following parents comment, it is important to be alert to available resources and both knowledgeable and focussed in attaining what is useful to their particular circumstances.

Understanding what's necessary, understanding what's available and understanding the organisation to get what's necessary from what's available. What we realised is that you have to be very purposeful to access things ... there's a degree of sophistication in knowing that [resources are] there and getting on with the people who provide it. Parent 7p23
I've learnt that... If someone is suggesting something to you... 'Hang on, they're seeing something that we don't. We're missing something.' Never knock it back and you'll generally find that yes, as time goes by... that's what we need to do.' Parent 9p37

Some parents rather than accept what is traditionally available, pursued creative paths in developing resources and processes in support of their child's future as this comment evidences.

We really do want to be creative and think outside the square. I've set up a business [based on her creative skills]. I've built up a website ...and a FaceBook page, so she's getting really good self-esteem and encouragement from people liking her things...and being able to at least supplement some part of her living expenses. Parent 7ap15

However, many parents particularly as they age, are challenged by care commitments impacting their available time and their motivation to seek out information resources as this parent's comment states.

[Parents] are so busy looking after a person with a disability, they don't go looking for help. As we get older, and we are ageing - we're less inclined to do that. Parent 11p29

Professional (Legal and Financial Services): Despite a general mistrust in accessing professional services it is evident that many parents would appreciate professional advice in their planning. Those parents who reported positive experiences often though through perseverance, trial and error, commented that to be of benefit to parents; professionals need to be accessible, instil trust and confidence in their clients, be knowledgeable about disability and the disability sector, willing to listen and be responsive to their needs. Cost management is an important consideration. The experience of parents who engaged in with pilot legal/ disability project and without cost is described here.

There was a meeting with several [lawyers]. We were being treated really well. They asked a lot of questions. Then we could put everything down, we could go through things. The meeting lasted quite a bit because we had to talk about different things. It was good. They made suggestions for things we hadn't thought of, so that was good. They put in a bit more detail about what [daughter] would want for the future. Things like wanting a holiday every year. Parent 10,10a pp21,22

Disability Services/ Sector: In their engagement with the disability sector regarding future planning parents commonly identified several factors of benefit to them in achieving their goals. Firstly, for people in the sector to have **knowledge and understanding of disability** and **about what parents might expect in the future**.

Working with people who do have an understanding of what [son's] disability is like, it's like a huge weight comes off your shoulder if you actually realise that they do understand where you're coming from....and

Knowing what to expect, because part of me doesn't really see what's in the future for [son], particularly if you're looking at when he turns 60 and he retires. Parent2a p26

Secondly, and as highlighted previously, parents wanted **information that is clear, concise consistent and reliable** on which to base their decision making and progress their planning.

We want a lot more information - and we knowgovernments change but we want the current information so we make at the moment the right decisions. Parent 4p48

Having positive long term **trusting** experience with a worker, knowledgeable about disability and their personal situation was critical for one parent. For them, **case management, someone to share the journey** with the family was viewed as essential to their future planning.

Case management is the critical thing. Coherent, coordinated case management. Once you've got a disabled child, you know that they're going to need management through all of this. Parent 9p 47

Government: Parents require from government, **commitment and understanding of the complex needs of children with disability, especially as they mature as adults and the lifetime challenges for parents in meeting these needs**. Some parents have after substantial lobbying, eventually received government support in achieving their desired planning goals. However, these parents still held concerns that with changes in government, these decisions may not be sustainable in the future. That said, active participation by government departments and officials was highly valued.

We want governments to honour what they promise. Because one comes in, they throw it out the window. They don't want to honour anything that went on beforehand. So if you've got a thing you've planned for - and governments to keep their words, to make - a sustained [decision] that will be there for the future, not changed continually. Parent 4&4ap49

Note: Impact of research interviews: It was notable that the research interview offered many parents the opportunity to think about and consider future planning options for their children. As these parents comment.

You've made me get a bit nearer to thinking about doing a legal thing more than we are. I can see we need to...have a good talk. Parent 8&8ap28

4. MESSAGES TO STAKEHOLDERS:

Just let me go to my grave knowing that somebody will take an interest in him and make sure he's okay. Parent 11p30

The following summary provides messages for involved stakeholders and parents in planning for the future of their adult children with cognitive impairment when parents are no longer able to manage their care or advocate for their children themselves.

Government

...to honour what is promised. Parents 4&4a

Parents identified a range of ***formal and informal strategies to assist with their planning*** in a complex and changing, social, political and economic environment that is increasingly concerned with finite financial and other resources. These included; ***visibility for disability governance issues, recognition of the complex issues involved in future planning***. While recognising the need for change within government, ***sustainable policy measures would assist planning outcomes***, especially in relation to the Disability Support Pension, funding packages and social housing. Parents identified the need for ***clarity in communication and information sharing that is consistent and reliable***, in particular, clear and detailed information regarding the ***financial implications of funding packages***. Preference was for ***a centralised information source with current knowledge and resources***.

Disability Sector Services

...someone to share the journey. Parent 9p47

As with the message to the government, parents valued engagement with service providers and workers knowledgeable about disability and the disability sector. Parents suggested ***ongoing education for service providers about future planning many recognising it is a long term and ongoing flexible process***. ***Alternative approaches to engaging parents in future planning*** may be considered as many parents had attended planning workshops or at least were aware of their availability but had not progressed with planning. Parents considered ***long term engagement with service providers*** useful in providing planning opportunities however ***'trust' was an important issue*** for them in developing these relationships. ***Case management was suggested as a practical, context driven approach for supporting families***, guiding and encouraging their decision making and planning.

Professionals

Working with people who have an understanding of what disability is like. Parent2ap26

Several factors limited parents' access to professional legal and financial services. Parents identified professionals' lack of knowledge of disability and of the disability sector, a continuing thread throughout this research project. ***Professionals and their professional bodies need to consider requirements for education and knowledge about disability to guide parents through available legal and financial mechanisms to progress the complex challenges of future planning***. In regards professional practice, ***professionals need to be available and willing to listen to clients to understand and respond to their specific needs***. To be of benefit to parents, ***information needs to be readily available, clear, consistent and accurate***. Parents are likely to avail themselves of professional advice where ***access is identifiable and cost effective***. Limited

access to private services suggests an increased *role for the Public Trustee* in providing parents with legal services.

Parents

Understand what's necessary, available, and the organisation to get what's necessary from what's available. Parent 7p23

Several points emerged from this study valuable in assisting parents to plan for their child's future. Firstly, that parents have *a clear vision and identifiable goals* to set a foundation for planning a quality future life for their child[ren]. To do so, requires parents to *clearly articulate their goals and needs to others* whether *family, friends, professionals or service providers*. This capacity assists parents to *purposefully and creatively seek resources beneficial to their vision and goals*. Parents' experiences demonstrated the value of *open, transparent and inclusive approaches* in planning and having *someone to share in their journey* whether that be a family member, friend or service provider.

For a number of reasons it is useful for parents to recognise planning as a *long term and ongoing project* rather than a short term task with immediate outcomes. With *regular reviews*, longer term planning *allows flexibility in adjusting to new and fluctuating situations*. Furthermore, a continuing process works to *ease often overwhelming feelings of planning as a formidable and daunting task*.

Finally, *maintaining optimum health and wellbeing* emerged as an important factor for parents in sustaining the *energy and motivation and initiative* required to progress with the complexities and challenges involved in future planning.

ACKNOWLEDGEMENTS

This project was funded from consultancy funds made available by Professor Jill Wilson, The School of Social Work and Human Services, The University of Queensland. We acknowledge the support and in kind assistance provided by Morrie O'Connor and staff of the Community Living Association, Nundah, Brisbane, Queensland. The guidance and support provided by Dr Kathy Ellem, Queensland University of Technology (QUT), Dr Lisa Bridle and Margaret Rodgers, Community Resource Unit (CRU), Miriam Taylor, Queensland Centre for Intellectual and Developmental Disability (QCIDD), Jeremy Ward, consultant to the disability sector and Dr Louise Whittaker, Southern Cross University (SCU) is greatly appreciated.

We are grateful for the time and assistance of the following disability support agencies; Down Syndrome Association, Homes West, Mamre, Parent 2 Parent and the Queensland Centre for Intellectual and Developmental Disability (QCIDD). We are especially indebted to the parents and agency staff who gave their time to participate in this study. Their commitment and willingness to share their personal journeys, knowledge and information is greatly appreciated.